

**DIVISION CIRCULAR #5  
(N.J.A.C. 10:41A)**

**DEPARTMENT OF HUMAN SERVICES  
DIVISION OF DEVELOPMENTAL DISABILITIES**

**EFFECTIVE DATE:** August 16, 2004

**DATE ISSUED:** August 16, 2004

(Rescinds DC #5, "Human Rights Committee", issued September 10, 1999.)

- I. **TITLE:**                   **Human Rights Committees**
- II. **PURPOSE:** The purpose of this chapter is to establish standards for the composition and operation of the Division of Developmental Disabilities' Human Rights Committees (HRC), as well as those in agencies under contract with or regulated by the Division, within the State of New Jersey and to ensure that HRCs operate as objective review boards in protecting the human and civil rights of individuals with developmental disabilities.
- III. **SCOPE:**       The rules in this chapter establish the composition and operation of the Human Rights Committees in developmental centers, regions of the Office of Community Services, and in the provider agencies and facilities under contract with or regulated by the Division.
- IV. **GENERAL STANDARDS:**

**NOTE:** The remainder of this circular is the Human Rights Committee as it appears at N.J.A.C. 10:41A.

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Acting Director

## **CHAPTER 41A HUMAN RIGHTS COMMITTEES**

### **SUBCHAPTER 1. GENERAL PROVISIONS**

#### **10:41A-1.1 Purpose**

The purpose of this chapter is to establish standards for the composition and operation of the Division of Developmental Disabilities' Human Rights Committees (HRC), as well as those in agencies under contract with or regulated by the Division, within the State of New Jersey and to ensure that HRCs operate as objective review boards in protecting the human and civil rights of individuals with developmental disabilities.

#### **10:41A-1.2 Scope**

The rules in this chapter establish the composition and operation of the Human Rights Committee in developmental centers, regions of the Office of Community Services, and in the provider agencies and facilities under contract with or regulated by the Division.

#### **10:41A-1.3 Definitions**

The words and terms used in this chapter shall have the following meanings, unless the context clearly indicates otherwise:

"Administrator" means the Chief Executive Officer of a developmental center, the Regional Administrator of Community Services, or the Executive Director of a provider agency under contract with or regulated by the Division.

"Affiliated" means a member of the HRC who is an individual served by the Division, family member, guardian, employee of the facility, or a person who has a contractual relationship with the Division.

"Behavioral Support Committee (BSC)" means a group of individuals who have clinical expertise and experience in evaluating strategies and approaches to behavior change. The charge of the BSC is to make judgments and recommendations regarding the safety, effectiveness, duration and need for proposed behavior interventions that are restrictive or intrusive in nature. The BSC review provides for the level of due process subsequent to that provided by the individual's interdisciplinary team.

"Chief executive officer" (CEO) means the person having administrative authority over, and responsibility for a State operated developmental center, or a private residential facility licensed under N.J.A.C. 10:47.

“Client record” means the organized compilation of documents that relate to the provision of services to an individual.

“Consensus” means a general agreement acceptable to all HRC members present.

“Division” means the Division of Developmental Disabilities.

“Executive director” means the person having administrative authority over a private agency that operates community based program(s) regulated by, or under contract with the Division.

“Human Rights Committee (HRC)” means a group comprised of affiliated and non-affiliated professionals, individuals served, advocates and/or interested persons from the community at large who function as an advisory body to the CEO, executive director, or regional administrator, on issues directly or indirectly affecting the rights of individuals served. At least two members are impartial outsiders, in that they would not have an interest represented by any other of the required members or the facility itself.

“Interdisciplinary Team” means a group that consists of the individual receiving services, the plan coordinator, the legal guardian, the DDD case manager, the parents or family member (if the adult desires that the parent or family member be present), advocates and friends, those persons who work most directly with the individual served, and professionals and representatives of service areas who are relevant to the identification of the individual’s needs and the design and evaluation of programs to meet them. The individual may identify additional persons who shall be invited to attend and participate.

“Non-affiliated member” means a member of a committee who is not employed by the service component, facility or agency. This includes members of the Developmental Disabilities Council or former residents and staff of the facility.

“Provider agency” means an agency or business that is under contract with the Division.

“Regional Administrator” means the person having administrative authority and responsibility over a region of Community Services.

“Restriction” means to place a limitation on an individual or group of individuals that prevents the carrying out of actions or activities and denies individuals their civil rights.

## **SUBCHAPTER 2. INDIVIDUAL RIGHTS**

### **10:41A-2.1 Rights of individuals with developmental disabilities**

- (a) Human rights issues shall include, but are not limited to, those delineated in the “Rights of the Developmentally Disabled” as set forth in N.J.S.A. 30:6D-1 et seq.
- (b) Individuals with developmental disabilities are entitled to exercise the same human and civil rights enjoyed by other citizens. These rights shall not be limited or modified unless the individual’s disability limits the exercise of these rights. Staff shall make efforts to assure that the human and civil rights of individuals with developmental disabilities are protected and exercised.
- (c) Individuals receiving services from the Division, Division staff, provider agency staff, parents, guardians, or other advocates for individuals may make referrals to the HRC through the HRC Chairperson.
- (d) Restrictions of an individual’s rights shall be documented in the client record.
- (e) All staff and contract providers shall advocate for and protect the rights of individuals with developmental disabilities in programs for which they are responsible. Staff and contract service providers shall utilize the structured form of the HRC as an assist in protecting the rights of individuals with developmental disabilities.

## **SUBCHAPTER 3. MEMBERSHIP OF THE HUMAN RIGHTS COMMITTEE**

### **10:41A-3.1 Appointment of members**

- (a) The Administrator shall appoint the members of the HRC for a two-year term. The term may be renewable.
- (b) New members must be trained prior to serving on the HRC as directed in NJAC 10:41A-3.5.
- (c) There shall be no more than one-third common membership of the Behavior Support Committee and the HRC of any service component, facility or agency.
- (d) The HRC shall consist of a minimum of five and a maximum of 15 members, at least one-third of whom shall not be employed by the component, facility or agency.

- (e) The HRC membership may be drawn from the following representative groups:
  - 1. Individuals with developmental disabilities, including individuals served;
  - 2. Family members and/or guardians of individuals with developmental disabilities;
  - 3. Persons who have experience and background with rights issues such as those in the legal profession, members of the clergy, ethicists, social workers;
  - 4. Persons who have prior experience serving on Human Rights Committees;
  - 5. Interested citizens from the local community; and
  - 6. Employees familiar with programs and services for individuals with developmental disabilities.
- (f) Members of the HRC who are not Division or agency employees will be required to sign a written statement that they will agree to protect individual information in accordance with Federal and State laws and Division rules. Persons who violate this subsection will no longer serve as a member of the HRC.
- (g) Regularly assigned members and the Chairperson and the Vice-Chairperson shall have voting rights.
- (h) The Division shall have the option of assigning an observer who is not a voting member to the HRC of any agency or facility with its own HRC.

#### **10:41A-3.2 Appointment of chairperson and vice-chairperson**

- (a) A chairperson and vice-chairperson shall be elected by a majority vote of each HRC. In developmental centers operated by the Division, the CEO will appoint the Chairperson.
- (b) The chairperson and vice-chairperson may be staff members or individuals from outside the developmental center, region, agency or facility.
- (c) The chairperson and vice-chairperson shall serve a two-year term to which they may be re-elected. In developmental centers operated by the Division, the CEO will re-appoint the Chairperson.
- (d) The vice-chairperson shall assume the responsibilities of the chairperson in his or her absence.

#### **10:41A-3.3 Filling vacancies created by un-expired terms**

- (a) Any HRC member who cannot complete his or her term shall communicate this in writing through the Chairperson to the Administrator at least two weeks before the date of resignation.
- (b) If the Chairperson cannot complete the term of his or her office, the Vice-Chairperson shall become the Chairperson for the remainder of the Chairperson's term. The HRC will elect, or the CEO will appoint, as appropriate under N.J.A.C. 10:41A-3.2(a), a replacement for the Vice-Chairperson, as soon as possible.
- (c) The Administrator shall appoint a replacement within 30 days of the creation of a vacancy on the HRC.

#### **10:41A-3.4 Removal of human rights committee members**

A committee member may be removed by the Administrator, for a good cause, based upon a two-thirds majority vote of the full committee. The member who may be removed shall not vote on the action.

#### **10:41A-3.5 Orientation to the Human Rights Committee**

Individuals who are appointed to the HRC shall receive, from the developmental center, regional office, facility or agency, at a minimum, informational and instructional material relevant to the services provided by the HRC.

### **SUBCHAPTER 4. RESPONSIBILITIES OF THE HRC**

#### **10:41A-4.1 Role of the Human Rights Committee**

- (a) The HRC shall exercise an advisory role to the Administrator.
- (b) The Administrator shall make the final decision on any issue regarding the rights of an individual receiving services, and when proceeding against the advice and recommendations of the HRC, shall document the substantive reasons for proceeding against the advice and recommendations of the HRC in the client record.
- (c) The orientation of the HRC shall be proactive and preventative. The committee shall recommend procedures and programs that safeguard the rights of the individual.

#### **10:41A-4.2 Meetings of the human rights committee**

- (a) The HRC shall meet at least every two months, and preferably every month.
- (b) The Chairperson shall also have the authority to call special and emergency meetings as necessary.
- (c) The decision making process of the HRC will be based on consensus.
- (d) A simple majority of the members of the HRC shall constitute a quorum. A quorum is necessary for all issues requiring consensus.
- (e) Any HRC member involved in the development or implementation of a proposed restriction will abstain from participation in the consensus process for that agenda item.
- (f) It is essential that the Administrator shall ensure that each committee be afforded a private meeting area and an atmosphere respectful of its independence and objectivity as a review group.
- (g) The Administrator will provide support staff to the Chairperson for completing tasks necessary for the HRC to function. These would include tasks related to material preparation, communication, and some aspects of information management.

#### **10:41A-4.3 General committee functions**

- (a) The functions of an HRC shall include, but not be limited to, the following:
  1. To advise the Administrator with regard to issues concerning the human and civil rights of individuals, bringing to his or her attention existing or potential infringements upon, or impediments to the free exercise of individuals' rights including recommendations for action;
  2. To contribute to the development or revision of policies and procedures directly relating to individuals rights;
  3. To review alleged or suspected violations of the rights of individuals or groups of individuals brought to the attention of the HRC and to recommend investigation of violations, as deemed appropriate by the Committee;
  4. To review behavior support plans which employ the use of procedures not prohibited by law or rule that may present an element of risk and/or restriction to an individual's rights; and

5. To review the proposed involvement of individuals participating in research projects.
- (b) The HRC shall have available to it all information that is necessary to perform its functions. The Committee shall have the right to observe programs and/or activities and conduct interviews in order to clarify a problem. Confidentiality of all information obtained shall be observed by the committee members, pursuant to N.J.S.A. 30:4-24.3.
- (c) The HRC shall have the right to request expert advice from outside the committee, as the committee deems appropriate.

#### **10:41A-4.4 HRC procedures**

- (a) The Chairperson will determine if the issues addressed in the referrals constitute an actual or potential infringement upon the free exercise of an individual's rights. If the Chairperson determines that the referral should not be reviewed by the committee, he or she shall draft an explanation for the next committee minutes and will review with the full committee, which will be the final arbitrator of any concerns regarding the relevancy of referral issues. If the request for HRC review was initiated by the individual or his or her legal guardian, the Chairperson shall provide a written explanation why the referral should not be reviewed by the HRC.
- (b) The HRC Chairperson will immediately review emergency referrals with the Administrator. Such referrals will be reviewed expeditiously during emergency meetings of the committee. Routine referrals will be addressed during the next scheduled committee meeting. The Administrator or guardians serving individuals may approve necessary emergency treatments. Such issues shall be reviewed by the HRC at a subsequent meeting.
- (c) To the extent practicable, an agenda shall be developed based upon referrals received and issues to be discussed and distributed in advance to all HRC members and guests.
- (d) The individuals with potential rights restrictions and their guardians will be invited to attend the meeting.
- (e) The individuals listed on the agenda will have their client records made available for the meeting, if necessary.
- (f) Chairpersons of any sub-committees shall present a summary of their agenda items for review.



- (g) The HRC members shall carefully review each issue and the data presented to analyze risk, evaluating alternatives and assuring rights are not recommended for restriction due to staff convenience. They will provide a consensus based upon this discussion. If necessary, the HRC will include recommendations for further actions to the respective Administrator.
- (h) The HRC will provide, in writing, to the Administrator, a copy of all recommendations within 10 working days of the meeting. The HRC Chairperson may provide a verbal recommendation to the Administrator if immediate implementation is deemed necessary.
- (i) The Administrator, or designee, will respond in writing to the HRC Chairperson, as well as the individual or his or her legal guardian, within 10 working days on routine referrals, or immediately on emergency referrals, regarding the acceptance, qualified acceptance, or non-acceptance of the recommendations. The Administrator will explain the basis for the HRC review and the rationale for his or her decisions.
- (j) The Chairperson will incorporate the Administrator's decisions and comments into the minutes of the meeting, which will be distributed to the committee members as the first agenda item of each meeting. The committee will review the Administrator's responses and implementation plan. The Chairperson will then outline the Administrator's decisions to the person or persons who presented the referral to the HRC.
- (k) A copy of the notification of the decision to the individual or his or her legal guardian, as indicated in (i) above, is to be maintained in the client record.
- (l) The HRC may request progress reports on the review recommendations through the Administrator.
- (m) Where disagreement exists between members, an effort shall be made to reach consensus. Where that is not possible, the HRC may vote on its recommendations and submit the results and positions reflected to the Administrator. The results of the vote shall be indicated in the meeting minutes.

#### **10:41A-4.5 Conflict of interest**

- (a) If any matter that arises in the Committee's deliberations should constitute a conflict of interest for a member of the Committee, that member shall abstain from voting on that issue.
- (b) A conflict of interest shall be determined to exist if the HRC member in question is the person who submitted the referral for review by the HRC,

that is, case manager; the person is a member of the BSC and it is a recommendation of the BSC that is the matter before the HRC; or the HRC member is any way is directly involved in the matter before the HRC. A final determination of conflict of interest will be the decision of the Chairperson.

- (c) Representatives of legal services, such as the New Jersey Protection and Advocacy, Inc., or other agencies, who may represent future individual interests, shall not be appointed members of an HRC as defined in this chapter. Their role and authority exist independent of this advisory body.

#### **10:41A-4.6 Dispute resolution**

- (a) Where the individual, guardian or advocate disagrees with the decision of the Administrator, the individual, guardian or advocate may submit a written statement of disagreement. This statement of disagreement shall be sent, prior to the next HRC meeting, to the Administrator for reconsideration and resolution. The Administrator shall notify the Chairperson of the HRC, in writing, of any disagreements and resolutions. This statement will be maintained in the client record.
- (b) If the individual, or his or her guardian or advocate, continues to disagree with the decision of the Administrator, the individual, or his or her guardian or advocate, may appeal the decision in accordance with N.J.A.C. 10:48-1.1.

### **SUBCHAPTER 5. RESPONSIBILITIES OF HRC CHAIRPERSON**

#### **10:41A-5.1 Responsibilities of the chairperson**

- (a) The chairperson of the Committee shall be responsible for the following:
  - 1. Presiding at meetings and performing all duties relevant to the office of Chairperson. The Chairperson shall also appoint sub-committee Chairpersons. The Chairperson shall have the power to call emergency HRC meetings;
  - 2. Ensuring the development and distribution of the agenda for each meeting;
  - 3. Assuring the review of any previously requested progress reports;
  - 4. Arranging for recording and transcription of minutes and that minutes are distributed and maintained;

5. Requesting consultation from outside the committee based upon a decision of the committee;
6. Ensuring the relevant, necessary meetings and reviews precede referrals to the HRC. The Chairperson may refer issues back to appropriate review panels, for example, Unusual Incident Review Committee; and
7. Educating the HRC members on their responsibilities.

#### **10:41A-5.2 Minutes of the meeting**

- (a) The Committee chairperson shall forward the meeting minutes to the respective Administrators, within 10 working days. In emergency situations, the recommendations shall be conveyed to the Administrators immediately, in person or by telephone. Minutes of the meeting shall be retained on file in the office of the respective Administrator and shall be available to members of the Division and surveying agencies, upon request.
- (b) Copies of the minutes shall be provided to the members of the Committee.
- (c) Copies of the minutes of Human Rights Committees, within the developmental centers and the regional offices, shall be forwarded to the Division Director within two weeks of the date of the meeting.
- (d) Regional HRC meeting minutes shall be forwarded to the Supervisor of the DDD Quality Improvement Unit.
- (e) The HRC minutes shall be marked as "Confidential Client Information" when individual information is present.
- (f) Documentation of the results of the HRC meeting, and all related documents that are specific to an individual, shall be placed in that individual's client record.
- (g) Minutes of the HRC are considered agency records. All individual identifying information contained in the HRC minutes shall be redacted prior to disclosure to the public.

#### **SUBCHAPTER 6. RESPONSIBILITIES OF AGENCIES UNDER CONTRACT WITH OR REGULATED BY THE DIVISION**

### **10:41A-6.1 Agency HRC**

- (a) Agencies should have their own HRC. Those agencies unable to establish an HRC may utilize an HRC within the Division Community Services Regional Office upon agreement with the Regional Administrator.
- (b) Any concern about the general functioning of the Committee shall be resolved between the CEO or executive director of an agency and the Chairperson of the committee. If these concerns cannot be resolved, the matter shall be referred to the Regional Administrator for resolution.

### **10:41A-6.2 Procedures for agency HRC**

Agencies using their own HRCs shall have procedures regarding the composition and operation of the Committee, which shall be included in the agency or facility manual and which shall be consistent with the provisions of this chapter.

### **10:41A-6.3 Membership of agency human rights committees**

- (a) The CEO of a private residential facility or executive director of an agency shall appoint members of the Committee, one of whom may be a Division employee.
- (b) The Division may assign an observer who is not a voting member of the committee. The observer shall be familiar with the agency or facility, its manual and the general committee functions.
  - 1. Should the observer have concerns about the agency or facility, he or she shall bring these concerns to the CEO of a private residential facility or executive director of an agency and Regional Administrator.
- (c) Any change in the membership of the committee shall be reported to the Regional Administrator within 30 days.

#### **10:41A-6.4 Notification of agency HRC meetings**

The agencies shall provide a schedule of the agency HRC meetings to the Regional Administrator and shall notify the Regional Administrator immediately of any emergency meetings.

#### **10:41A-6.6 Minutes of meetings**

- (a) The minutes of agency HRC meetings shall be forwarded to the Regional Administrator for review in accordance with N.J.A.C. 10:41A-5.2.
- (b) A copy of the agency HRC minutes is to be available for review by Division staff as authorized by the Division Director.
- (c) Committee members and Division observers shall be provided with copies of the minutes.